BMC Psychology

https://doi.org/10.1186/s40359-026-05065-5

Article in Press

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Received: 11 April 2026

Accepted: 22 June 2026

Published online: 24 June 2026

Cite this article as: Smorti M., Ponti L., Ghinassi S. *et al.* Disease acceptance and socio-familial support in late adolescents and young adults with cardiomyopathy: a pilot study. *BMC Psychol* (2026). https://doi.org/10.1186/s40359-026-05065-5

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Disease acceptance and socio-familial support in late adolescents and young adults with cardiomyopathy: A pilot study

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Abstract

Background: Cardiovascular disease acceptance has been little studied in late adolescents and young adults with cardiomyopathy and mostly regarded as integration into personal rather than social identity. Integration in social relationships is also relevant, given the role of social support in

facilitating adaptation and acceptance of chronic illness. Therefore, this study explored whether perceived support from family, friends, and romantic partners was associated with disease acceptance, controlling for disease-related factors.

Methods: A cross-sectional study involved 68 individuals with self-reported cardiomyopathy aged 16–30 years (M = 24.68, SD = 3.83) recruited through Italian Cardiomyopathies Association. Participants completed a survey including socio-demographic and disease-related data, and two self-report measures assessing disease acceptance and perceived social support from family, friends, and partners. Hierarchical regression analysis was performed to evaluate the association between different facets of perceived social support and disease acceptance, controlling for disease-related data.

Results: The final model accounted for 16.2% of the variance in disease acceptance. Among the variables considered, higher perceived family support was associated with greater disease acceptance, whereas the presence of an implantable cardioverter-defibrillator was associated with lower disease acceptance.

Conclusions: These preliminary findings suggest that the social context, particularly family relationships, may be relevant to disease acceptance during late adolescence and young adulthood. Family-focused support may represent a useful component of transition care aimed at promoting adaptation and self-management in young people with cardiomyopathy.

Keywords: cardiomyopathy; disease acceptance; late adolescents; self-management; social support; transition care; young adults

Introduction

Cardiomyopathies constitute a complex spectrum of myocardial rare diseases with an estimated annual incidence of 1.1–1.5 cases per 100,000 patients from birth to 18 years of age [1]. Moreover, although epidemiological patterns may vary by diagnosis and age, global data indicate a higher prevalence of cardiomyopathy in males than in females [2]. Despite being rare, cardiomyopathies represent a significant cause of morbidity and mortality in young patients [3]. Management of cardiomyopathy can be particularly challenging during late adolescence and the young adulthood phases because, with the transition from pediatric- to adult- oriented care, the management of the disease progressively passes from parents to the affected youths with an increased risk for non-adherence and interruption in cardiac follow-up [4]. Acceptance of cardiovascular disease—conceptualized as living with the condition without judgment, integrating it into one's identity, maintaining engagement in daily activities, adhering to prescribed treatment regimens, dietary and lifestyle modifications, and medication adherence—appears to be relevant for improving adherence and self-management in young patients [5]. Acceptance may be particularly challenging due to lifestyle restrictions and physical activity limitations, even in asymptomatic patients, which can negatively affect social engagement and delay the acquisition of adult

identity [6]. Disease acceptance involves integrating the condition into one's identity, a process shaped through ongoing social interactions with parents, peers, and romantic partners [7]. Moreover, acceptance may be hindered by lifestyle changes and activity restrictions, which can interfere with future planning and daily participation in social contexts [6]. The social environment may act either as a risk or protective factor depending on the quality of interactions with parents, peers, and romantic partners. Parental support may enhance understanding of the diagnosis, promote adaptive coping, and encourage appropriate recreational engagement, thereby supporting acceptance [8]. Nevertheless, no studies to date have investigated the relationship between peer support and acceptance of cardiac pathology in late adolescents and young adults, despite the well-known impact of peer exclusion and secrecy on psychological adjustment [9]. Disclosure of cardiac disease to peers is often selective or avoided due to fears of social exclusion, which may influence acceptance and adherence, yet this relationship remains unexplored in young cardiomyopathy patients [9]. Likewise, while romantic relationships may be associated with adjustment and heart disease management behavior, most studies have focused on adulthood and elderly, overlooking the adolescent and young adult population [8].

Based on these premises, the aim of this study was to explore the role of different facets of social support on cardiovascular disease acceptance

controlling for disease-related data that are known to influence disease acceptance [7].

Method

Procedure and participants

A cross-sectional study was conducted in accordance with the Declaration of Helsinki, and it was approved by the Bioethical Committee of the University of Pisa (Italy) (nr. 13/2022). Data were collected between December 2023 and June 2024 from individuals with self-reported cardiomyopathy affiliated with the Italian Cardiomyopathies Association. Inclusion criteria were age 16-30 years, proficiency in Italian, and a self-reported diagnosis of cardiomyopathy. G Power software defined the required sample size using a priori statistical power analysis [10]. The analysis indicated that at least 59 participants were required for a statistical power of 95%, an effect size of 0.40, and an alpha of 0.05.

The Italian Cardiomyopathies Association contacted 186 potentially eligible individuals by email and invited them to express their interest in participating in the study. Of these, 52 declined to participate, while 134 expressed interest and received the survey link. Among those who received the link, 68 completed the questionnaire and 66 did not complete it. Therefore, the final sample consisted of 68 individuals (79% males) aged between 16 and 30 years (Mage = 24.68; SD = 3.83).

Measures

An ad-hoc questionnaire was administered to collect socio-demographic (i.e., gender, age, year of scholarship, occupational status, living arrangement) and disease related data (years since diagnosis, diagnosis phenotype, familial cardiomyopathy, pharmacotherapy, presence of Implantable Cardioverter-Defibrillator - ICD).

The *Cardiovascular Disease Acceptance and Action Questionnaire* (CVD-AAQ) [11] was used to measure the individual acceptance of thoughts and feelings related to cardiovascular illness and the degree to which such thoughts and feelings interfere with valued action. The CVD-AAQ consisted of 7 items asking participants to indicate their thoughts and feelings on a Likert-type scale ranging from 1 (*Totally disagree*) to 7 (*Totally agree*) with higher scores indicating lower disease acceptance. In the present study, internal consistency was acceptable (α = .70).

The *Multidimensional Scale of Perceived Social Support* (MSPSS) [12] was used to assess the level of perceived social support. The MSPSS consists of 12 items requiring respondents to rate their agreement on a Likert scale ranging from 1 (*Totally false*) to 7 (*Totally true*), considering the perceived social support from family, friends, and partner. Higher scores indicate a higher level of perceived social support. In the present study, the internal consistency values were excellent (α = .93, .90, and .80 for family, friends, and partner, respectively).

Data analysis

Collected data were analyzed using IBM SPSS Statistics, version 31. Descriptive statistics are reported for socio-demographic and clinical variables. Chi-square tests and t-test analyses were conducted to examine gender differences in socio-demographic and disease-related data.

Hierarchical regression analysis was performed to evaluate the association between different facets of perceived social support (step 2) and disease acceptance, controlling for disease-related data – i.e., years since diagnosis, familial disease (0=no; 1=yes), pharmacotherapy (0= no; 1= yes), and presence of an Implantable Cardioverter-Defibrillator (0= no; 1= yes).

Results

Table 1 reports the sociodemographic, clinical and psychological characteristics of participants and the comparison between males and females. Differences emerged only in age and living arrangement, with females being older than males and more likely to live alone, but less likely to live with parents. No gender differences emerged in disease acceptance and perceived social support from family, friends and partner.

Table 1. *Sample description*

	Males (n=53)	**Females (n=15)**	**Total (n=68)**	**Statistics**
Sociodemographic data				
Age, years Mean (SD)	24.11 (3.74)	26.67 (3.58)	24.68 (3.83)	$t_{(66)} = -2.358$, $p = .021$
Years of education, mean (SD)	14.70 (2.42)	16.07 (2.37)	15.00 (2.46)	$t_{(66)} = -1.940$, p = .057
Occupational Status, n (%)				$\chi^2_{(2)} = 0.509$, $p = .775$
Student	20 (37.7)	5 (33.3)	25 (36.8)	
Employed	29 (54.7)	8 (53.3)	37 (54.4)	

Unemployed	4 (7.5)	2 (13.3)	6 (8.8)	
Living arrangement, n (%)				$\chi^2_{(3)} = 10.683$, $p = .014$
Living with parents	36 (67.9)	5 (33.3)	41 (60.3)	
Living alone	3 (5.7)	4 (26.7)	7 (10.3)	
Living with partner	10 (18.9)	6 (40.0)	16 (23.5)	
Living with friends	4 (7.5)	-	4 (5.9)	
Clinical data				
Years since diagnosis, Mean (SD)	7.51 (5.36)	8.33 (7.27)	7.69 (5.79)	$t_{(66)} = -0.484$, $p = .315$
Cardiomyopathy phenotype, n (%)				$\chi^2_{(2)} = 0.946$, $p = .623$
Dilated	7 (13.2)	3 (20.0)	10 (14.7)	
Hypertrophic	44 (83)	12 (80.0)	56 (82.4)	
Arrhythmogenic	2 (3.8)	-	2 (2.9)	
Familial cardiomyopathy n (%)				$\chi^2_{(1)} = 1.611$, $p = .204$
Yes	22 (41.5)	9 (60.0)	31 (45.6)	
No	31 (58.5)	6 (40.0)	37 (54.4)	
Pharmacotherapy, n (%)				$\chi^2_{(1)} = 0.328$, $p = .567$
Yes	36 (67.9)	9 (60.0)	45 (66.2)	
No	17 (32.1)	6 (40.0)	23 (33.8)	
Presence of ICD, n (%)				$\chi^2_{(1)} = 0.603$, $p = .438$
Yes	16 (30.2)	3 (20.0)	19 (27.9)	
No	37 (69.8)	12 (80.0)	49 (72.1)	
Psychological data				
Disease acceptance	19.06 (7.53)	18.33 (7.82)	18.90 (7.54)	$t_{(66)} = 0.326$, $p = .746$
Perceived social support from family	23.72 (4.43)	24.73 (4.74)	23.94 (4.48)	$t_{(66)} = -0.773$, $p = .442$
Perceived social support from friends	20.81 (4.73)	20.93 (4.27)	20.84 (4.62)	$t_{(66)} = -0.090$, $p = .929$
Perceived social support from a partner	22.94 (4.42)	23.40 (4.36)	23.04 (4.38)	$t_{(66)} = -0.354$, $p = .724$

Note: ICD = Implantable Cardioverter-Defibrillator

Results of the hierarchical regression analysis are reported in Table 2. Before interpreting the model, regression assumptions were examined. Visual inspection of the histogram, normal P-P plot, and residual scatterplot did not indicate major deviations from normality or relevant violations of

linearity and homoscedasticity. Multicollinearity was not a concern, with tolerance values ranging from .780 to .945 and VIF values ranging from 1.058 to 1.282. Based on these preliminary checks, the regression coefficients were interpreted. In Step 1, disease-related variables accounted for 7.3% of the variance in CVD-AAQ scores. The addition of perceived social support facets in Step 2 accounted for an additional 8.9% of variance. Overall, the final model accounted for 16.2% of the variance in CVD-AAQ scores, indicating modest explanatory power. Since higher CVD-AAQ scores indicate lower disease acceptance, positive coefficients in Table 2 indicate lower disease acceptance, whereas negative coefficients indicate greater disease acceptance.

Table 2. *Hierarchical regression analysis*

	B	***SE***	***β***	***t***	***p***	***1***
Step 1						
Years since diagnosis	-0.154	0.174	-0.118	-0.882	.381	
Familial cardiomyopathy	1.626	1.908	0.108	0.852	.397	
Implantable Cardioverter-Defibrillator	4.643	2.183	0.278	2.126	.037	
Pharmacotherapy	-1.211	1.948	-0.076	-0.621	.537	
Step 2						
Years since diagnosis	-0.166	0.170	-0.128	-0.976	.333	
Familial cardiomyopathy	1.723	1.884	0.115	0.915	.364	
Presence of ICD	4.749	2.131	0.285	2.229	.030	
Pharmacotherapy	-1.038	1.924	-0.066	-0.539	.592	
Perceived social support from family	-0.504	0.224	-0.300	-2.249	.028	
Perceived social support from friends	-0.086	0.219	-0.053	-0.394	.695	
Perceived social support from a partner	0.144	0.230	0.083	0.625	.535	

Note. ICD: Implantable Cardioverter-Defibrillator; VIF = Variance Inflation Factor. Because higher CVD-AAQ scores indicate lower disease acceptance, positive coefficients indicate lower disease acceptance, whereas negative coefficients indicate greater disease acceptance.

Discussion

This pilot study provides preliminary evidence on disease acceptance in a cohort of late adolescents and young adults with cardiomyopathy. In the hierarchical regression analysis, the presence of an ICD was associated with lower disease acceptance. This finding is in line with previous research showing that ICD acceptance may be lower in younger individuals, especially when the device is implanted for primary prevention and has not delivered appropriate shocks [13]. One possible interpretation is that the ICD may represent a concrete and persistent reminder of cardiac risk, making the integration of the disease into everyday life more complex. Qualitative studies have suggested that, for some patients, the ICD not only symbolizes protection but also serves as a constant reminder of the risk of sudden cardiac death, reinforcing awareness of both mortality and the underlying cardiac condition [14]. These aspects may be particularly relevant in late adolescence and young adulthood, when individuals are progressively constructing autonomy, social identity, and future plans, while also being expected to acquire increasing responsibility for disease management [15]. More broadly, one possible hypothesis is that disease acceptance may be especially challenging in asymptomatic or presymptomatic phases, when the illness and its potential consequences may be less directly perceived in daily life [16].

Furthermore, this pilot study suggests that higher perceived family support was associated with greater disease acceptance in late adolescents and young adults with cardiomyopathy, whereas perceived support from friends and romantic partners was not significantly associated with disease acceptance. This finding is relevant because late adolescence and young adulthood are usually characterized by increasing autonomy and by the growing importance of peer and romantic relationships [17,18]. However, young people with chronic cardiac conditions may continue to rely substantially on their family, particularly when parents remain involved in medical appointments, treatment decisions, and everyday disease management. This interpretation is consistent with recommendations for family-centred psychosocial care in pediatric and congenital cardiology, which emphasize the importance of supporting both patients and families across developmental phases [15,19]. Given that most participants lived with their parents, it is possible that family support was more closely related to disease acceptance than other sources of support. One possible explanation is that family members, being aware of the young person's disease, may support everyday disease management, thereby facilitating disease acceptance. This result may also be partially explained by the specific Italian cultural and social context, where emerging adults often live in the parental home until around 30 years of age, potentially delaying emancipation from parental figures [20].

The absence of significant associations between perceived support from friends or romantic partners and disease acceptance may be interpreted in two complementary ways. First, support from friends and romantic partners may become more relevant later in life, as autonomy from the family increases and peer and romantic relationships become more central in everyday life. Second, the role of peer support may depend on disclosure processes. Peers may not always be aware of the young person's cardiac condition, particularly when the disease is not disclosed or openly discussed. In this case, perceived support from friends may be less directly related to disease acceptance. Future studies should therefore examine whether peers are aware of the disease and whether disclosure processes influence the association between peer support and disease acceptance. This may be particularly relevant because young people with chronic disease may sometimes be reluctant to share their health status in order to feel socially integrated among peers [21,22]. From this perspective, disease acceptance may not only involve the integration of the illness into personal identity, but also the extent to which the self with cardiac disease is integrated into significant peer relationships. This interpretation is consistent with the concept of illness identity, which refers to the degree to which a chronic illness is integrated into one's identity [23].

Considering the above, the contribution of the present pilot study lies in its focus on disease acceptance in late adolescents and young adults with cardiomyopathy, a population that has received limited attention in

psychological research. The study also adds to the literature by distinguishing between different sources of perceived social support, suggesting that family, friends, and romantic partners may not be equally related to disease acceptance during this developmental phase. Overall, these findings highlight the need to consider disease acceptance not only as an individual process, but also in relation to the relational contexts in which young people manage and integrate their cardiac condition.

Implications for practice

These preliminary findings suggest the potential relevance of counseling in the transition from adolescence to young adulthood, particularly at certain stages of the illness. In the present study, the presence of an ICD was associated with lower disease acceptance and this result, together with previous evidence indicating that younger age may be associated with lower ICD acceptance in adults with congenital heart disease [13], suggests that counselling should pay particular attention to how young patients understand and integrate the meaning of the device into their daily life. In the asymptomatic phase, for example, counseling should promote acceptance of the illness in order to prevent the enactment of risky behaviors due to the lack of perception of the illness itself. This may include discussing the meaning of preventive behaviors, such as dietary recommendations or physical activity restrictions when clinically indicated, and helping young patients understand that the absence of symptoms or

ICD shocks does not necessarily mean that the disease is not present or clinically relevant.

Furthermore, the present findings showed that higher perceived family support was associated with greater disease acceptance. Therefore, the importance of parental support in the acceptance of illness should also be taken into consideration during counseling and transition care. Although transition care increasingly aims to promote the patient's autonomy, family support may represent a relevant relational factor in this process, particularly during late adolescence and young adulthood. This is also consistent with recommendations for transition care and family-centred psychosocial care, which emphasize the importance of supporting both young patients and their families during developmental transitions [15,19]. It may therefore be useful to support parents in helping young patients by organizing meetings that promote a proper balance between support and encouragement for autonomy. Although the support assessed in the present study was emotional in nature, it may also reflect a broader family environment that supports the process of disease acceptance. From a clinical point of view, professionals may consider involving parents in counselling or educational meetings, while being careful not to reinforce excessive interdependence.

Limitations and implications for research

Although interesting, the results of this study should be interpreted with caution due to several limitations. First, the study involved a relatively small

convenience sample. Although the sample size was defined a priori using G*Power and is consistent with the exploratory and pilot nature of the study, as well as with previous research on emerging adults with cardiac disease [24], the limited number of participants may have reduced statistical power and increased the risk of unstable estimates, particularly in regression models including multiple predictors.

An additional limitation concerns the number of individuals who received the survey link but did not complete the questionnaire. Since no socio-demographic, clinical, or psychological data were available for these non-completers, it was not possible to compare them with participants who completed the survey or to perform sensitivity analyses. Therefore, a possible completion bias cannot be excluded. Future studies should collect minimal anonymized information on individuals who do not complete the survey, in order to better evaluate recruitment and retention processes.

The small sample size also prevented subgroup analyses by cardiomyopathy phenotype. Therefore, the findings should be considered preliminary and require replication in larger samples that allow researchers to examine whether disease acceptance and its psychosocial correlates differ across diagnostic subgroups.

It is also important to note that the regression model accounted for a limited proportion of variance in disease acceptance (16.2%). This suggests that disease acceptance in late adolescents and young adults with cardiomyopathy is likely to be a multidimensional process. Other factors not

assessed in the present pilot study may also be relevant, including clinical and physical factors (e.g., symptom burden, medication side effects, exercise capacity, and functional limitations), psychological and cognitive factors (e.g., illness uncertainty, prognostic anxiety, illness perceptions, and self-efficacy), and socio-environmental factors (e.g., peer stigma, family dynamics, and support during healthcare transition). This limited explanatory power further supports the need for future studies including broader clinical, psychological, and socio-environmental variables.

Moreover, the sample was unbalanced in terms of gender, with a predominance of male participants. Although this distribution is consistent with previous epidemiological evidence showing a higher prevalence of cardiomyopathy in males than in females [2], the gender imbalance in the present sample limits the generalizability of the findings and prevented us from examining whether the associations between perceived social support and disease acceptance differed by gender. Future studies should recruit larger and more gender-balanced samples, or at least samples that allow stratified analyses, to examine the potential role of gender in disease acceptance and perceived social support.

In addition, participants were recruited through a patient association, a recruitment strategy that may have introduced selection bias. Individuals affiliated with patient associations may differ from non-affiliated patients in terms of disease awareness, access to information, coping strategies, perceived social support, and willingness to participate in research.

Therefore, the present findings may not be representative of all late adolescents and young adults with cardiomyopathy, and future studies should examine these associations in clinically recruited samples.

A further limitation concerns the reliance on participants' self-reported cardiomyopathy diagnosis, as no medical records or physician-confirmed documentation were available to verify this information. Given the clinical heterogeneity of cardiomyopathies, the absence of diagnostic verification may have limited the internal validity of the study and the precision of the clinical characterization of the sample. In particular, it was not possible to confirm diagnostic subtype, disease severity, symptom burden, or treatment history. Future studies should replicate these findings in clinically verified samples and collect more detailed clinical information on cardiomyopathy phenotype, clinical severity, symptom burden, treatment history, and functional limitations.

Declaration

Acknowledgments section. Authors thank individuals for their participation and the Italian Cardiomyopathies Association for the support given in the recruitment of participants.

Authors' contribution. Conceptualization: MS; Methodology: LP, SG; Formal analysis and investigation: AC; Writing – original draft preparation: MS, LP, SG; Writing – review and editing: MP, IO, FC; Supervision: MS, FC.

Declaration of conflicting interest. The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding statement. The authors received no financial support for the research, authorship, and/or publication of this article.

Ethical approval and informed consent statements. The study was conducted in compliance with the principles of the Declaration of Helsinki and was approved by the Bioethical Committee of the University of Pisa (Italy) (nr. 13/2022). Informed consent to participate was obtained from all participants prior to data collection. Participants were required to provide their informed consent in the first section of the online survey before accessing the questionnaire.

Consent for publication. Not applicable.

Data availability statement. The data that support the findings of this study are not openly available due to sensitivity reasons and are available from the corresponding author upon reasonable request.

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